A SURVEY OF KNOWLEDGE AND ATTITUDE OF THE GENERAL PUBLIC TOWARDS EPILEPSY IN LAHORE, PAKISTAN

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ABSTRACT

Objective: To explore the ideas people have towards epilepsy.

Design: The qualitative methods were used in the first step while in second stage a cross sectional design was used.

Place and duration of study: The study was conducted at the Ganga Ram Hospital medical outpatients in Lahore, Pakistan from November 2003 to April 2004.

Subject and Methods: A focus group was conducted to explore the beliefs people have towards epilepsy. Seven patients and their carers who were attending medical outpatients participated in this group discussion. On the basis of this a survey form was formulated. This form was used to gather information from a larger sample in the next step in which all those attending this service during the study period were contacted. Those who consented were asked questions from the survey.

Results : Nearly 90% respondents were aware of epilepsy. Ninety three percent respondents believed that epilepsy is treatable. Nearly 95% people believed that if epileptic patients are treated, they recover completely. However, there were variations in people's beliefs about causes of epilepsy as well as how and who should treat it.

Conclusion: Nearly half of our sample derived from a big urban centre believed in unscientific causes of epilepsy. There is urgent need to educate general public on this important issue.

Key words: Knowledge, Attitude, Epilepsy, Pakistan.

INTRODUCTION

Stigma related to chronic health conditions such as HIV, leprosy, tuberculosis, mental illness and epilepsy is a global phenomenon with a severe impact on individuals and their families, and on the effectiveness of public health programs.

It has been claimed that 75 per cent of people with epilepsy in Pakistan are not aware that they have the condition[1]. Patients with medical as well as mental health problems consult practitioners of complimentary and alternative medicine. The main reasons for this are; the proximity, affordability, availability, family pressure and the strong opinion of the community[2]. In a study of the population attending these services and the practices of the native faith healers sixty-one percent of attendees were given a research diagnosis of mental disorder: major depressive episode (24%), generalized anxiety disorder (15%) or epilepsy (9%). The classification used by faith healers is based on the mystic cause of disorders: saya (27%), jinn possession (16%) or churail (14%)[3].

The research in this area mainly comes from the Western countries. We found very few studies from South East Asia looking at stigma of Epilepsy. Randhkrishnan et al[4] found that ninety-nine percent of the respondents had read or heard about epilepsy. Thirty-one percent and 27% thought epilepsy was a hereditary disorder and a form of insanity, respectively. About 40% of the respondents felt that individuals with epilepsy could not be properly educated or employed. Eleven percent would object to their children having contact with epileptic children. In another Indian study[5] of the attitude of students it was found that nearly 60% of students thought that epilepsy was a form of insanity. Western Medicine as form of treatment was preferred by more than half of the respondents; however, many had faith in exorcism and visiting religious places as ways to cure epilepsy. Half of the students considered epilepsy a hindrance to education, employment, and marriage. Thirteen percent would be unwilling to sit adjacent to or play with a child with epilepsy.

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An English study[6] using a qualitative interview method compared South East Asians from different faith groups. The belief that epilepsy is caused by spirit possession (Muslims) or attributable to sins committed in a past life (Sikhs and Hindus) were reported as being widely held among South Asians living both in the UK and the Indian subcontinent, although few informants themselves subscribed to such views. Although, most patients were compliant with conventional medication, those with poor response were more likely to turn to traditional South Asian therapies. Most informants used both treatments simultaneously. Khan et al[7] in a transcultural study comparing a Kashmiri population with US population found that the use of adjunctive spiritual therapies was more prevalent in the Kashmiri sample, and the use of alternative, non-pharmacological therapies was more prevalent in the American sample. Quality of life for the Kashmiri patients sampled was found to be poorer in terms of educational and occupational opportunities, feelings of stigmatization, and openness with others about the illness. Although the two patient populations interviewed differed in their access to resources and approaches to the disorder, both samples were found to be similar overall in many attitudes and practices relating to epilepsy and its treatment.

In our literature search we did not find any studies carried out in Pakistan on this issue. We therefore decided to assess the knowledge of the general public and their attitudes towards epilepsy since this can have profound effect on their help seeking behaviour. The aim of this study was to explore the attitudes and knowledge people have towards epilepsy.

SUBJECTS AND METHODS

It was a mixed design study with qualitative methods used in the first step while the second step was a cross sectional study. A focus group was conducted to explore the beliefs people have towards epilepsy. Seven patients and their carers who were attending medical outpatients participated in this group discussion. On the basis of this a survey form was formulated. This form was used to gather information from a larger sample in the next step.

The study was conducted at the Ganga Ram Hospital medical outpatients in Lahore, Pakistan. All those attending these services during the study period were contacted. Those who consented were asked questions from the survey.

We contacted all those attending the medical clinics but not those who were attending the psychiatric or neurological departments since we wanted to keep our sample as close to general population as possible. Analysis was carried out using SPSS v 12.0.

RESULTS

Mean age of the respondents was 28.4 years, (SD=11.25) and majority (84.2%) were women. Table 1 shows demographic characteristics of respondents.

Nearly 90% (51) reported that they are aware of a condition called epilepsy, or at least have heard the name of it and 28% (16) reported they knew someone with the condition. Table 2 shows views on causes of epilepsy.

Table 1

Demographic details (total=57)

		Frequency	Percent
Gender	Female	48	84.2
	Male	9	15.8
Education			
	No education	1	1.8
	Student	17	29.8
	Primary	9	15.8
	Matric	9	15.8
	Masters / professional	11	19.3
	Missing	10	17.5
Marital status	Single	36	63.2
	Married	21	36.8

Table 2

People's views of causes of Epilepsy

	Frequency	Percent
Ghost	2	3.5
Physical Reasons	21	36.8
Psychological Reasons	16	28.1
Fear	4	7.0
Inherited	5	8.8
Physical reasons as well as inherited	3	5.3
Physical as well as psychological reasons	2	3.5

Ninety three percent (53) respondents believed that epilepsy is treatable. Nearly 95% (54) people believed that epileptic patients if treated do recover completely. Table 3 shows the views about treatment of epilepsy.

Nearly half of the respondents said that epilepsy can be treated medically. However other half said that the treatments for epilepsy are non medical.

A significant number of people believed that epilepsy can be treated by doctors. Interestingly more people believed that epilepsy can be treated by the psychiatrists than those who believed that epilepsy can be treated by a neurologist or neurosurgeon. Table 4 shows respondents views of who can treat epilepsy.

When asked if you will marry a person with epilepsy, 47% (27) replied yes. When asked will you marry

Table 3

Respondents views of treatment of epilepsy (possible treatments)

Possible treatments	Frequency	Percent
Jooti Sunghana	3	5.3
Taveez	3	5.3
Dam darood	5	8.8
Hakeem	11	19.3
Medical treatment	30	52.6

Table 4

Who can treat epilepsy?

		Frequency	Percent
a	Pir Faqir	1	1.8
b	Maulvi	2	3.5
c	Doctor	22	38.6
d	Neurologist	1	1.8
e	Neurosurgeon	5	8.8
f	Psychiatrist	17	29.8
	Spiritual healers & doctors	2	3.5
	Spiritual healers & neuro surgeons	6	10.5
	Spiritual healers & psychiatrists	1	1.8

a person who has epilepsy in the family, 73% (42) said yes. Only 19% (11) believed that epilepsy is a contagious illness. Nearly twenty percent (11) of the people surveyed said if someone close to them had epilepsy they will hide the diagnosis from others.

DISCUSSION

Most of our respondents were young women. Ganga Ram Hospital is a teaching hospital attached with a female only medical college and it is possible that more women attend this hospital than men. Only one respondent was uneducated. This is hardly surprising when one considers the fact that Lahore is a big city and the population has better access to education and health facilities compared with remote areas. This is one serious limitation of this study in that the results might not be applicable to older women, people living in remote areas or even to men living in Lahore.

Nearly all the respondents reported that they were aware of a condition called epilepsy. They at least had heard the name of it and nearly one third reported they knew someone who had got the condition. This might also be due to our population sample being drawn from a big city. One third respondents believed that epilepsy is due to physical factors, while another one third believed that epilepsy could be due to psychological or emotional reasons. A small number also believed in other (mostly para normal) explanations of epilepsy or multiple explanations. Only 3.5% believed that epilepsy could be due to ghosts and 7% thought is could be due to fear. It will be important to mention here that by fear usually people mean fear induced by seeing spirits or other paranormal phenomenon. Although only 9% believed that epilepsy can be caused through hereditary causes, nearly half of them said they will not marry a person with epilepsy. Although most of the respondents felt safer in marrying a person who had someone with epilepsy in the family. The fact that although only a small number of respondents believed in hereditary causes of epilepsy but they still didn't want to marry a person with epilepsy means that people might have other explanations of causes of epilepsy. One such reason could be the belief that epilepsy is a contagious illness which was shared by one quarter of the respondents. Another reason for not marrying a person could be high stigma attached to the condition, which was evident from nearly the same number of respondents who said that if someone close to them had epilepsy they will hide the diagnosis from others.

High perceived stigma and non medical explanations of causes and spread of the illness are important variables which could lead to delays in seeking treatment because people not only hide patients from others but also a non medical explanation makes it less likely for them to bring the patient to medical professions. The same problems might be involved in epileptic patients not getting married or at least getting married with great difficulties (marriage in Pakistan is mostly arranged and very much like a business partnership between two families in which each tries to get the most from the deal, and an illness with high stigma can be a big handicap). This can lead to patients being socially isolated and can cause further psychological and social problems not only for the patients but also for the families. It would have been interesting to explore these issues further to see if men hold different views on these subjects, but the number was too small to conduct further analyses. These are however, important issues which need to be dealt with through effective community education and information at the primary and secondary care level.

The finding that one third of the respondents believed in physical causes is in line with the view expressed by nearly half of the respondents that epilepsy can be treated medically. What was confusing however, was the finding that nearly all of them believed that epilepsy is treatable and that epileptic patients if treated do recover completely. This does not fit in with the views expressed by the respondents in general. The only possible explanation could be that they believed that medical as well as non medical treatments work. The non medical treatments included; jooti sunghana (putting a

shoe near the nose of a person who is having an epileptic attack), taweez (religious verses or some writings on a piece of paper which the affected person then keeps with him), dam darood (blowing air towards the person after saying some quranic verses) and hikmat (derived from the old Greek or Indian medicine).

Another issue related to the causes and possible treatments of the epilepsy was "who could treat the epileptic patients". We were interested in this issue since in our focus group discussions we found that people mentioned different healthcare professional who could treat epilepsy. Lack of structure and organization in the healthcare system, poor differentiation between primary and secondary care services and poorly organized or sometimes non existent referral system are important considerations in this regard. The issue is further complicated by the fact that most professionals have to run their private practices due to poor salaries in the government sector, which might even explain to some extent the lack of a referral system. We found that people who believed that epilepsy can be treated by psychiatrists were more than those who believed that epilepsy can be treated by a neurologist or a neurosurgeon. This could be explained by two possibilities. First, as mentioned above lack of a referral system and additionally poorly set professional boundaries and ethical standards and secondly, most patients in the psychiatric outpatient clinics present with dissociative disorders with convulsions which might be misleading to the non professional observer. At the end of the day someone has to treat these patients and what counts is; better medical care, better prognosis and leading a healthy life with minimum deficits.

CONCLUSION

We found that members of general public who come from a big city and most of whom were educated and attending one of the main hospitals had negative opinions and views regarding epilepsy and patients with epilepsy. Most of them believed in non physical causes and treatments of the epilepsy. There is a need to repeat this work with better methodology and bigger samples from other populations in Pakistan. There is also a need to focus on this very important issue in public health programs.

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